

TESTIMONY BEFORE THE
JOINT COMMISSION ON HEALTH CARE
ON
THE MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES
WAIVERS

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Good morning, Chairman Houck, Vice-Chairman Hamilton, Secretary Tavenner, and members of the Commission. I'm Sandy Hermann, parent of a child with a disability and the Community Resource Coordinator at Care Connection for Children, Children's Hospital of The King's Daughters in Norfolk, Virginia. I am also a member of the Virginia Board for People with Disabilities; however I am not speaking on behalf of the Board today.

As a parent of a 12 year old daughter with very significant medical, physical, and cognitive needs, I understand the importance that a Medicaid Waiver was able to make in my daughters and our families life. A Medicaid Waiver has provided my daughter, Felicia, with the services and supports needed to remain in the community instead of an institution. Due to the extensive waiting lists of two of our Medicaid Waivers, the MR Waiver and the DD Waiver, many individuals have not been as lucky as my daughter and been able to receive the supports needed to remain living in the community. Could you imagine being the parent of a child with Cerebral Palsy, Autism, or Down syndrome and not being able to ever obtain any assistance?

Imagine having to make the decision to institutionalize your child because the state will pay for services in an institution but not those needed for the child to be raised at home. And for parents who make the decision to keep their child at home, imagine how it feels to never have a break from the constant caregiving responsibilities that your child requires, often including complex medical care? Without support, our family would have been unable to provide the total care that Felicia requires. With support, Felicia is able to live with her parents and her brother and attend public school in a regular education classroom. She is making progress on her SOLs. She ice skates, goes to the movies and has friends, all of which would not be possible without the support of the waiver. In my line of work I see many children who are not as fortunate as Felicia, living lonely, segregated lives in nursing homes and ICFs-MR. Virginia must make a firm commitment to supporting full inclusion of ALL persons with disabilities, regardless of diagnosis, in all facets of community life by eliminating the waiting lists for ALL Medicaid Waivers. At the current rate of funding, the waiting lists will simply continue to grow with no chance of elimination or even significant reduction.

As you have already previously heard, Virginia has seven different Medicaid Waivers with different eligibility criteria, services provided, waiting lists, providers of services, and places of entry into the system. It is very confusing for an individual with a disability or an overwhelmed family member just trying to make it through the day to figure out the

correct path within that process. A system with a single point of entry must be developed for individuals with disabilities in Virginia.

As you know, Virginia lacks a state agency responsible for policy development, service planning, and service provision for individuals with developmental disabilities (DD) who do not have a concurrent diagnosis of intellectual disability. The Secretary of Health and Human Resources recently convened an advisory group to make recommendations on the development of an implementation plan focused on providing a state agency home for people with autism and other developmental disabilities. This group was formed as a result of the work conducted by the Joint Commission on Health Care Behavioral Subcommittee. The development of a DD agency would reduce the fragmentation of the disability services system while developing an inclusive service system not based on disability diagnosis. It would help eliminate agency silos and reduce competition for the state's limited resources.

With limited resources, we must also ensure that a fair and equitable way of determining how Medicaid Waiver slots are allocated is maintained. Currently the Developmental Disabilities (DD) Waiver utilizes statewide administration with emergency slots available whereas the Mental Retardation Waiver determines slot distribution on a local level. While the argument can be made that individuals at each local CSB are better able to determine those most in need, is it really fair and equitable to determine that only those within a specific locality with the most urgent needs at the moment a slot become available are able to be funded. What if the individual with the most urgent needs resided in the locality next door to the city that received the Waiver slot? With such a huge waiting list, we must ensure that the variations between localities in a person's access to and waiting period for the MR Waiver are addressed when local decisions instead of statewide determinations are made. In its 2008 *Biennial Assessment of the Disability Services System in Virginia*, the Virginia Board for People with Disabilities (VBPD) recommended that consideration be given to an objective, independent study by JLARC of DD and MR waiver waiting list administration.

Another inconsistency between the MR and DD waivers is with respect to case management. Once Medicaid Waiver eligibility has been established, individuals should be provided with a choice as to what agency provides their Case Management and Waiver services, as is currently done in the DD Waiver. In our current MR Waiver system, the Community Services Board (CSB) serves as the single point of entry for an individual with an intellectual disability and the sole provider of case management services. Choice must be maintained for individuals with disabilities. Imagine being told that you were only allowed to go to one specific restaurant to eat or one particular car dealer to purchase a car for the rest of your life, just because of the specific disability diagnosis that you have?

Under the MR Waiver, the CSB is responsible for completing the screening to determine whether an individual is eligible for an MR Waiver, placing the individual on a Waiver waiting list if they are determined eligible, providing case management services for the individual, determining whether the individual receives a waiver slot when one becomes

available in their specific locality, providing the Waiver services if selected by the individual, and annually re-determining eligibility of the individual for the waiver.

Under the DD Waiver, eligibility screenings are completed by the Department of Health Child Development Clinics. Once eligibility has been determined by the clinic, the individual selects a Case Manager from the list provided by the Clinic. The case manager is prohibited from being the provider of any Waiver service, other than Consumer Directed Service Facilitation. Annual reevaluations are completed by the Department of Medical Assistance Services to ensure the individuals continued eligibility for the Waiver.

In its 2008 Biennial Assessment: ” VBPD stated: *“regardless of the excellent intentions and work of the CSBs’...there is an inherent systemic conflict of interest whenever a single entity (whether private or public) is responsible for the multiple roles of determining initial and annual eligibility, providing case management, service planning, service delivery, service funding, and service oversight.”* Virginia must ensure that as it moves forward in its service planning, transparent lines are maintained within its service system to support full inclusion of persons with developmental disabilities in all facets of community life.